Published in final edited form as:

Br J Dermatol. 2020 June ; 182(6): 1490–1492. doi:10.1111/bjd.18818.

Identifying barriers to care and research in hidradenitis suppurativa: findings from a patient engagement event

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Dear Editor, Hidradenitis suppurativa (HS) is a painful, disfiguring, chronic inflammatory disease that disproportionately affects underserved populations. Delayed diagnosis¹ and lack of uniformly effective therapies for patients with HS^{2,3} have contributed to suffering, despair and reluctance to seek healthcare and participate in research. In recent years, over 60 000 patients have found support and health information through Facebook communities. Our objective was to engage patient leaders of support communities for patients with HS on Facebook to identify barriers to seeking clinical care and participating in research.

We conducted an in-person meeting with six U.S.A.-based HS patient leaders (all female; median age 37.5 years, interquartile range 37–38.75) representing seven HS Facebook groups comprising > 25 000 patients with HS in October 2018, as well as three dermatologists, two researchers and one member of the Facebook Community Partnerships Team. The meeting comprised discussions led by the patient leaders designed to understand the experiences of patients with HS with the medical community. Patient leaders received discussion questions prior to the meeting and were asked to query their Facebook HS patient communities so they could accurately represent their views. With permission, discussions were transcribed verbatim.

Comments collected were from patient leaders only, who described in their own words what they perceived in their groups. At the in-person meeting, a rapid qualitative thematic analysis and summary of the patient leader quotations were conducted, reviewed and refined

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Conflict of interest: M.A.L. has received fees for participating in advisory boards for AbbVie and Janssen, and consulting fees from Incyte, BSN and XBiotech, and Almirall; however, there is no conflict with the present study. H.B.N. has received grant funding from AbbVie and consulting fees from 23andme. H.B.N. and M.A.L. are Hidradenitis Suppurativa Foundation board members. C.A. receives patient referral fees from M3 Global Research.

with input from the patient leaders. Preliminary themes were identified and the initial conceptual framework was developed with patient leaders at the meeting. Publication of the meeting proceedings was not originally intended; however, as engagement with the HS patient community is important to overcoming barriers to HS care and research, we subsequently obtained institutional review board approval and explicit written consent for publication of deidentified quotations from all participants.

The discussions led by the patient leaders identified five barriers to seeking healthcare and participating in research, including (i) practitioners' lack of knowledge about HS, (ii) difficulty accessing specialists knowledgeable about HS, (iii) poor communication, (iv) distrust of the medical community and (v) patients' experiences of HS. Representative quotations for each barrier identified are presented in Table 1.

The first identified barrier to seeking care and participating in HS research was lack of practitioners' medical knowledge about HS. Misdiagnosis and diagnostic delay were major frustrations, leading individuals to approach online communities with diagnostic questions. Lack of knowledge about pain and mental health comorbidities in HS were other major gaps identified. Conversely, favourable experiences with the medical community included interactions with practitioners who provided patient-centred care, were 'honest about treatment outcomes' and 'were open to trying [novel treatments]'.

The second identified barrier was difficulty accessing specialists with expertise in HS. Patient leaders relayed that patients had limited or no access to practitioners knowledgeable about HS. All patient leaders stated that patients with HS encountered challenges accessing mental health resources and psychosocial support.

The third identified barrier was poor practitioner communication with patients. Patient leaders reported that patient preferences were often not considered when formulating treatment plans and that lack of empathy and respect were common features of medical encounters, contributing to dehumanization.

Patient leaders asserted that patients with HS want to participate in research to find ways to better their own lives and the lives of other people with HS ('there is lots of value of research'); however, collective negative experiences with practitioners have contributed to a fourth barrier to seeking healthcare and participating in research: 'rampant distrust' of the medical community. Erosion of trust has led patients with HS to seek support and medical advice from social media platforms.

The fifth barrier to seeking care and participating in HS research was the patient experience of living with HS. Patient leaders described the significant pain and stigma of living with HS, and the resultant suffering, despair and profound isolation. They indicated that 'pain [was] the most important factor' impacting quality of life, function and ability to attend school or work. They reported prominent depression and suicidality among online community members and described the value of support in alleviating isolation and restoring hope.

In conclusion, as information about the burden of HS has grown, HS research has increased and new therapies are being developed.^{4,5} Addressing the barriers to care and research identified herein may help to improve clinical care and advance urgently needed HS research.

Acknowledgments:

the authors would like to thank the people living with HS who shared their experiences and constructive suggestions for improvements.

Funding: UCSF provided travel, accommodation and dinner for this event. Facebook provided breakfast and lunch at the event, and ground transportation for patient leaders.

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Table 1

Selected quotations from hidradenitis suppurativa (HS) patient leaders

Barrier	Quotations
Knowledge	
Lack of knowledge among healthcare professionals	It took years to be diagnosed with HS It's so rare to see a doctor who knows about HS All appointments begin with diet, smoking, weight, hygiene
Access	
Limited access to HS specialists	My PCP said that it isn't his job to help me Getting in to see a dermatologist is like getting to see the president Our plastic surgeon said he doesn't make money working with HS patients. HS is a money-losing condition It's very difficult to get treatment or support even if you have a doctor Some providers do send timely mental health referrals Plenty of people online are considering suicide due to the pain
Limited access to mental health resources	
Communication	
Poor communication	Doctors have problems with listening [Doctors] think they are experts and are unwilling to listen to our preferences You already feel bad enough about yourself. You don't want to be judged immediately Do not discuss weight while people are nude My teenage daughter was told she smelled [Doctors] are dehumanizing you [Doctors] treat you like a drug seeker
Lack of empathy and respect	
Trust	
Distrust of the medical community	Distrust of doctors is rampant People say I don't trust the medical field, therefore they are going to hide it, they are going to suffer
Patient experience of HS	
Experience of living with HS	Pain is the most important factor It became a nightmare. I was suffering physically and emotionally For years I thought I had an unknown STD My two sisters had the same thing and didn't speak about HS because they were too embarrassed. It's an isolating and debilitating disease My daughter couldn't graduate high school because of a gym requirement

Barrier	Quotations
Role of social media support groups	I had to advocate for myself
	Everything deteriorates
	When people stop seeing doctors, they turn to [social media]
	Every day we get 20 requests [to join our social media group]. I had no idea there was anybody else, is what they think
	They are my family. You are me, we are going through the same things

PCP, primary care physician; STD, sexually transmitted disease.